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Emergency and Scheduled Respite Care for Caregivers of Persons with Dementia: a Proposed Program

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INTRODUCTION

Respite care is defined as providing the primary caregiver with relief or a reprieve from care commitments on a short-term or emergency basis. (cite 1) Despite a demonstrated interest (cite 2) in need for respite care programs, our research has shown that scarce resources exist via a statewide dementia respite program administered by Vermont’s five Area Agencies on Aging (cite 3). Grants are small and many families do not fall within the eligibility requirements. In FY2010, only 290 families across the state met eligibility requirements (physicians’ diagnosis of dementia, income less than 300% of poverty line, unpaid caregiver, primary residence in VT) and were awarded limited funding for the provision of outside care (up to $750.00 each). For many of these families, this money is typically used to provide substitute care when the primary caregiver is not available. To date, there is no true emergency respite program in place for caregivers. This has placed a strain on families and day facilities, particularly when situations arise in which a caregiver is unable to pick up their family member due to an emergency situation. Our goal was to demonstrate the feasibility of a respite program to address this need.

RESULTS

We began with a literature review and discussions with key agencies involved in the well-being of patients with dementia and their caregivers. These agencies included: The Visiting Nursing Association (VNA), Dept. of Disabilities, Aging and Independent Living (DAI), Vermont Chapter of Alzheimer’s Association, and the Vermont Area Agencies on Aging. Based on the input of existing community agencies, we drafted a program proposal for emergency and scheduled respite. Recognizing the paucity of funding sources as a chief limitation to current models, we developed a survey to assess the feasibility of a volunteer-based program. An electronic survey was sent via Survey Monkey to the volunteer pool at Fletcher Allen; members of the UVM community; agencies that participate in and need resources exist via a statewide dementia respite program

PROPOSED PROGRAM

Based on our results and investigations into local resources we would propose the following program and community partners:

- **Model**
  - *Program Administration by the Visiting Nurse Association of Chittenden and Grand Isle Counties*
  - *Utilization of community volunteers*
  - *Background Checks - Training Program*
  - *Reimbursement of out-of-pocket expenses*
  - *Specialized care in caring for patients with dementia*

**DISCUSSION**

The results from our survey demonstrate feasibility for a volunteer-based program. Of 95 responses to our survey, 71 individuals responded that they would be willing to volunteer. Of that group, 42 individuals were willing to volunteer with expenses paid and an additional 29 were willing to participate if provided a nominal fee in addition to their expenses (Table 1). Additionally, we surveyed willingness to participate in a training program and background check (100%), interest in coverage of emergency and/or scheduled respite care (graph 1), timing of care (chart 1), regular commitments (chart 2), and donated hours (graph 2).

**COMMISSION RESOURCES AND POTENTIAL FUNDING**

**Potential Community Partners:**

- **Administration:** Visiting Nurse Association of Chittenden and Grand Isle Counties
- **Training:**
  - ElderWisdom system of Caregiving: adaptation of current curriculum geared to non-medical caregivers.
  - Alzheimer’s Association: classroom and online training
  - ElderWise system of Caregiving: adaptation of current 70 hour curriculum geared to non-medical caregivers.
  - Medicaid Home and Community-Based Services Waiver Program
  - Alzheimer’s Association: classroom and online training
  - ElderWise system of Caregiving: adaptation of current 70 hour curriculum geared to non-medical caregivers.

**CONCLUSION**

Previous research has demonstrated a need for additional resources for caregivers of patients with dementia. Our group has demonstrated the feasibility of a volunteer-based program for provision of emergency and scheduled respite care. In addition, our group has identified potential community partners and fiscal resources that should be further pursued to bring this much needed service to the community at large.

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